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ABSTRACT

Two out of three Canadian women will care for a chronically ill or disabled family member. Caregiving is a valuable task that can simultaneously have great emotional rewards and significant physical, emotional, and financial costs. The time spent out of the paid labor force because of caregiving responsibilities averages 11.5 years for women versus 1.3 years for men. Many caregivers may not ask for help or be aware of assistance available to them. Even with adequate support and recognition, caregivers often experience overwhelming feelings of grief, guilt, and resentment, especially when without continued informal support caregiving becomes impossible. Caregivers must receive increased emotional, physical, and financial recognition and support for the important work they do. Informal support networks and formal services must be made available and affordable to those who need them. Caregivers should be paid for the work they do, and costs related to their employment should be recognized. Caregivers can begin by identifying needs and gaps in services and move toward advocating for adequate funding and policy changes. (Concluding the publication are lists of print, audiovisual, and community resources dealing with home care services, Canadian caregiver support groups and agencies, and respite care.) (MN)

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CREATING
PRAIRIE CRONIES

Lifecycle Learning Sheet

ED 366 738

GIVING AND TAKING CARE

Joyce Deutscher cared for her elderly mother full-time for two years until she died at 94 years of age. Mrs. Dew had suffered a series of strokes, and her progressive memory loss made it impossible for her to continue living alone in her rural home. When she moved into the city to live with her daughter, Mrs. Dew left behind a caring community who had helped Joyce provide care for eight years. Joyce was aware that this was a difficult transition for her mother, who she described as a sensitive, intelligent and independent woman.

Joyce willingly made the decision to take care of her mother although it restricted her own life. Mrs. Dew could not be left alone and became disoriented if left in the care of others. As a result, Joyce became very isolated.

Just as Mrs. Dew developed ways and means of coping with her memory loss, Joyce developed coping mechanisms for being a primary caregiver. She and her mother enjoyed going for long drives together. Joyce would pack a thermos of coffee for her mother to drink, which gave her fifteen minutes to slip into a store or run a quick errand along the way. She would have to return to the car before the coffee was gone and her mother became disoriented. That time became less and less until Joyce couldn't leave her mother alone at all.

As Mrs. Dew's caregiving needs intensified over the last ten years of her life, Joyce had reduced her high school teaching load to part-time and then retired early partially to accommodate her responsibilities to her mother. Her pension was considerably reduced as a result of her employment decisions. Had hers been the only household income at the time, it would have caused greater financial strain.

The greatest joy that Joyce experienced as a caregiver was knowing that what she was doing was very important and useful. She knew her mother appreciated all that Joyce did for her, even if she didn't say it often. Joyce didn't resent the time she spent giving care to her mother, it was, in her words "just what had to be done".

Joyce felt that she was grieving while her mother was still alive. Seeing her mother gradually lose who she was and all that she

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Seniors' Education Centre
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had been was a painful process. Her death in some ways was a relief.

After her mother died, it was difficult for Joyce to join the outside world again. She had voluntarily chosen to limit her own activities and organize her life around her mother's needs. Many things that had been put on hold temporarily, now had to be dealt with. By becoming involved in volunteer activities and meeting new friends, Joyce gradually shed the inward mind-set that had helped her to cope with being a full time caregiver.

In Joyce's opinion, a variety of supports are needed for caregivers to choose from depending on their particular situation and needs. Support groups and respite care are services that she didn't take advantage of during her time as a caregiver, although she realizes they would have helped. At the time she would have appreciated simple gestures such as home baking or an occasional visitor, just to know that others cared.

Her advice to women who are currently caregivers is to make a list of areas where they feel they want or need help. Then find out if such help is available. Joyce recognizes from her own experience that people who give care need to take care.

BASIC ISSUES OF CAREGIVING

- Two out of three Canadian women will take care of a chronically ill or disabled family member.[1]

- After only 18 months, 60 per cent of caregivers begin to experience a break down of their own health.[2]

- 30 per cent of women caregivers work full-time outside of the home and have children under eighteen. Ranging in age from 40-60 these caregivers are called "the sandwich generation".[3]

Caregiving for an elderly loved one is an important and valuable task, which can have significant rewards and costs. While caregivers may willingly accept their role, the restrictions on their lives can cause considerable physical, emotional and financial stress.

Women average 11.5 years out of the paid labour force, mainly due to caregiving responsibilities of the young and old, while men average 1.3 years.[4] This has a direct effect on women's lower earnings and pensions. Leaving the workforce and accepting less demanding jobs to accommodate caregiving duties has hidden financial costs to caregivers which are often not recognized.

Caregiving can go on for more than 20 years. Just one generation ago, extended families shared the task of caring for their elders. In today's society, caregiving is done by individual women, often in isolation from the community. Resting on the shoulders of one person, caregiving can be a very demanding responsibility. Duties range from assistance with transportation and shopping, to help with personal hygiene, to 24 hour home care. The

1 From "When the Day Comes", VHS, National Film Board, 1991.
2 Ibid.
3 Caregiving: How to Care for your Elderly Mother and Stay Sane. E. Jane Mall. New York: Ballantine Books, 1990, p. 1.
4 "Failing America's Caregivers: A Status Report on Women Who Care." Transition. Vol. 20, No. 1, March 1990, p.9.

extent of care expands as the health of the elderly person deteriorates.

Even with adequate support and recognition, caregivers often experience overwhelming feelings of grief; guilt and resentment can also easily develop. Researchers have found that caring for a loved one whose condition is deteriorating can lead to depression, anxiety, frustration, helplessness, sleeplessness, lowered morale and emotional exhaustion.[5]

Caregivers perform the most important work of struggling to preserve the quality of life for the people they love. While they cannot do it alone, many caregivers may not ask for help nor be aware of assistance that is available to them. One study revealed that older women who provide care to their husbands are reluctant to use support services.[6] One reason for their reluctance is the fear of poverty. Since caregiving can go on for years, the caregiver may face an ongoing drain on her finances. Consequently, she may try to do without support services for as long as she can.

Whereas most elderly men are cared for by their wives, elderly women who require care depend on both formal and informal support networks. Typically, elderly women receive support from daughters and daughters-in-law. However, many of these younger women face the insurmountable task of caring for elderly relatives in addition to participating in the workforce and fulfilling traditional duties, such as raising children and attending to home responsibilities. Given the demands on younger women, elderly women who need care often receive some support from a variety of home care services.[7]

There may come a time when informal caregiving, for whatever reasons, is no longer possible and the older individual may have to be placed in a special care home. It is important to recognize and honour this decision knowing that it is made with the same sensitivity and love required by the caregiving relationship. Planning ahead is important as waiting lists for special care homes may be two years or longer. If possible, make the move when the older person is able, physically and emotionally to handle the transition. Sometimes, the most difficult task of caregiving is learning to let go. The decisions are never easy. Getting support and recognition is critical to the well-being of the caregivers.

NECESSARY CHANGES

Caregivers must receive increased emotional, physical and financial recognition and support for the important work they do.

The informal support network of family, friends and neighbours can help to meet the challenge of caring for dependent older individuals. Formal services such as meal-on-wheels and respite care must be made available and affordable to those who need them. The formal and informal sectors can cooperate in preserving the highest possible quality of life for elderly loved ones and those who care for them.

Support groups for primary caregivers provide an opportunity to share thoughts, feelings and coping strategies. Starting a group can be as simple as calling a district home care service

5 Ibid.

6 "Caregivers: Strategies to make it possible for the most weary caregiver to carry on", Foresight - Canada's Magazine for Retirement Planning, November, 1991, p. 50.

7 Women and Aging - An Annotated Bibliography, 1986 - 1991. Monica Mori and Janet McNern. Simon Fraser University: Gerontology Research Centre, 1991, p.vi.

and asking for the names of other primary caregivers.

Caregivers should be paid for the work they do. Women have provided endless hours of unpaid labour in the areas of caregiving and homemaking. Too often they face their older years without pensions and must rely solely on old age security.

Costs related to caregivers' employment should be recognized. The Canada and Quebec Pension Plan regulations include an employment "drop-out period", used to calculate the individual's contributory periods. The regulations could be amended to recognize the time spent caring for an elderly person who requires full-time assistance with the tasks of daily living. Special fringe benefits related to the care of a dependent child, such as leaves of absence, could also be applied to the care of a dependent senior. This would allow caregivers to take necessary time away from work without penalty to their employment or pension plan.[8]

Caregivers can support one another and work together to make changes in areas that affect their lives. They can begin by identifying needs and gaps in services, and move towards advocating for adequate funding and policy changes.

As a society, we need to recognize the unpaid work of caregiving and homemaking. We can begin to work together to find ways to share the load and ease the burden.

PRINT RESOURCES

Taking Care: a self-help guide for coping with an elderly chronically ill, or disabled relative. Jill Watt and Ann Calder. Vancouver: International Self Counsel Press, 1986

Twelve Weeks in Spring: The inspiring Story of Margaret, who is dying, and her team of caregivers. June Callwood. Toronto: Lester & Orpen Dennys Ltd., 1986.

Taking Care of Your Aging Family Members: a practical guide. Nancy R. Hooyman and Wendy Lustbaden. New York: The Free Press, 1986.

A Handbook of Practical Care for the Frail Elderly. Merlin A. Taken, Mary Ann Anichine, Steve Anderson, Robert A. Weagant, and the Community Care Project. University of Illinois School of Social Work, Oryx Press, 1986.

Daughters of the Elderly - Building Partnerships in Caregiving: edited by Jane Norris, Indiana University Press, 1988.

The 36 Hour Day: A family guide to caring for a person with Alzheimer's disease, related demential illness and memory loss in later life. Nancy L. Mace and Peter V. Rabins, M.D. The John Hopkins University Press, 1981.

Failure Free Activities for Alzheimer's Patients: A guideline for caregivers. Carment Sheridan Cottage Books, 1987.

"Failing America's Caregivers. A Status Report on Women Who Care." Transition. Vol. 20, No.1, March 1990, pp. 8 - 11. (Available from Creating Prairie Cronies).

"Listening as the Language of Love: Caring for an Aging Parent". Mariel Norton. In E.D. Gray (ED.), The Sacred Dimensions of Women's Experience. Wellesley, Mass.: Round Table Books, 1988, pp. 85-91.

8 The NACA Position on Informal Caregiving: Support and Enhancement. The National Advisory Council on Aging. Ottawa: Minister of Supply and Services, 1990, p. 1-3.

Dying at Home: a family guide for caregiving. Andrea Sankar. Baltimore: John Hopkins University Press, 1991.

Most of these books are available through your local library.

AUDIO-VISUAL RESOURCES

When the Day Comes
VHS
National Film Board
1990
When there are too few community programs available to care for ill or disabled seniors, the responsibility often falls on family members, particularly women. *When the Day Comes* focuses on four women, 45-75 years old, who discuss the physical and emotional stresses of providing care for a friend or loved one. Many caregivers suffer from exhaustion and isolation, requiring help themselves in order to cope. The video suggests changes to Canada's health care system and encourages greater community involvement in the care of the ill or frail elderly.

Living with Dying
VHS
National Film Board
1991
Albert is terminally ill. His wife, Margaret, is his primary caregiver. Their loving relationship has lasted 40 years and they continue to enjoy one another, sharing many activities. *Living With Dying* shows how this is made possible through a local community health program. These programs provide regular house visits from a nurse who helps the family acquire the physical and medical aids to keep pain under control and facilitate daily tasks. Friends and neighbours offer social, psychological and spiritual support, ensuring that Albert experiences a quality of life that is difficult to achieve in a medical institution.

Don't Take My Sunshine Away
VHS
National Film Board
1991
The innovative care schemes of five North American and European communities are examined in this film which focuses on the diversity of health and social services offered to an aging population. Sensitive to the need for maintaining independence and social contact, professional and non-professional caregivers alike display creativity in personalizing their caregiving. For the elderly, as well as the disabled and frail, these aids result in a prolonged period of autonomous living and improved quality of life. this film is dedicated to "the rights of all of us, when we are old."

COMMUNITY RESOURCES

HOME CARE SERVICES

Saskatchewan Home Care Program
3475 Albert Street
Regina, Saskatchewan S4S 6X6
787-7896

In Saskatchewan, there are 45 district home care offices, providing a variety of services throughout the province. The Saskatchewan Home Care Program, through Sask Health, is designed to help people who cannot manage by themselves entirely and who need some care and support to remain at home. District home care services can provide information on the availability of support services to caregivers in their communities. A list of all district home care offices is available. For more information, write to or telephone the Saskatchewan Home Care Program or your district home care office.

Wascana Home Care
District 15 Inc.
4211 Albert Street
Regina, Saskatchewan
586-0355

In the Regina area, Wascana Home Care provides assessment and coordination, meal service, nursing and homemaking service, and home maintenance service.

Home Care - Saskatoon and District # 45
201-310 Idylwyld Dr. N.
Saskatoon, Saskatchewan S7L 0Z2
934-2112

A health care service dedicated to assisting individuals in achieving independence in their homes.

Regina Assessment and Placement Service
1400-14th Avenue
Regina, Saskatchewan S4P 0W5
359-4242

Offers a centralized service for assessing needs, receiving applications and coordinating placements for persons requiring long-term care in special care homes and extended families. Provides respite care in special care homes for maximum of thirty days.

CAREGIVER SUPPORT GROUPS AND AGENCIES

Alzheimers Association of Saskatchewan
224-408 Broad Street
Regina, Saskatchewan S4R 1X3
949-4141

Provides family support, offers public education and promotes research into the cause and treatment of dementia. Alzheimer's Support Groups help families and caregivers of an impaired person maintain and increase feelings of self-worth and control. By sharing problems, group members help each other to cope more effectively. There are Alzheimer's Family Support Groups in 33 communities throughout Saskatchewan. A phone list can be obtained by writing to or telephoning the Alzheimer's Association Office.

Regina Palliative Care Inc.
4101 Dewdney Ave.
Regina, Saskatchewan
359-2665

Offers comfort and care to people facing life threatening illness and to their families. Services include coordinated care of the terminaily ill patient, on-going education and support to health caregivers and public, and bereavement follow-up.

Regina Pioneer Village
(see description below)

RESPITE CARE

V.O.N. Regina Sitter Service for Adults
3906 Gordon Road
Regina, Saskatchewan S4S 6Y3
586-5771

Offers an opportunity to take some time out. Sitter service volunteers can provide non-medical care and companionship while you go out to relax for a few hours or to attend appointments or run errands. The cost of the service is minimal and many of the sitters have experience caring for people with Alzheimer disease.

Regina Pioneer Village Adult Day Care Program
430 Pioneer Dr.
Regina, Saskatchewan S4T 6L8
757-5646 local 246

This program aims to provide services and support at a minimal cost to cognitively-impaired adults and their caregivers, making it possible for them to

experience an optimum quality of life while continuing to live in the community. The purpose is to provide respite to caregivers while maintaining the highest possible level of function and enrichment through structured programming and social interaction for the cognitively-impaired adult. A family support group meets every month.

NOTE: Many special care homes throughou the province provide adult day care or respite care. Contact the special care home in your community and inquire about services.

THE LIFECYCLE LEARNING SHEETS are a publication of CREATING PRAIRIE CRONIES (CPC), the Saskatchewan older women's network. Funded by the Health Promotions Directorate, Health and Welfare Canada, CPC is an outreach and education program of the Seniors' Education Centre, University Extension, University of Regina. For more information please contact Ruth Biaser, coordinator for CREATING PRAIRIE CRONIES at 779-4729.

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